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ABSTRACT

This article on systems change focuses on the efforts of a mentally retarded man with cerebral palsy and his advocates to obtain the resources necessary for him to be able to leave a nursing home and live independently. First, the article identifies two kinds of change: change within the system's rules and changing the rules or the system itself. The specific issue is framed as a description of changes needed in a system which would pay for someone to live in a nursing home but not for the necessary personal assistance to live independently. The young man's testimony before the Georgia Department of Medical Assistance Hearings is included in full. Also included is the text of his request for assistance, which he distributed to anyone possibly able to help his cause. This effort resulted in over more than 100 people offering help and eventually a place of his own with the necessary support services. Lessons for systems change learned from this example are summarized and include the need to build a base group for systems change; learn the political processes for changing the system rules; find a question that challenges the beliefs that shape the system's rules; and always keep a human face on the issues. (DB)

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ONE DAY AT A TIME:
CHANGING A SYSTEM TO REALIZE A DREAM

by
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One Day at a Time

Changing a System to Realize a Dream

John O'Brien, Ray Browning, and Connie Lyle O'Brien*

Ray is one of the pioneers in our home state of Georgia who have worked with their allies to change the way services are delivered. They prove beyond doubt that people with severe disabilities can live safely, and usually comfortably, in their own homes, with assistance from agencies and staff that they can hire and fire. After fourteen years as a "heavy care" patient in a nursing home with more than 100 other disabled and elderly people, Ray moved into his own place. Every day for more than two years, Ray has shown that people who need a lot of assistance with everyday matters like getting dressed and eating and using the toilet and getting from place to place and reading and writing don't have to live in institutions or nursing homes or group homes or staff supervised apartments. Like anyone else, they can live in their own home if they have adequate assistance. There have been many problems to solve and some hard times, and there will be many more difficulties. But those problems, and labels like "severe cerebral palsy" and "uncorrectable vision deficits" and "moderate mental retardation", don't have to determine where you live, who you live with, how you spend your day, and how you get the help you need.

Ray has helped to change the rules in our state's service system and to make the world of possibilities bigger for a growing number of people with disabilities. Along the way he has learned a lot about how to play a part in making social change. It is very important to him to teach other people what he has learned. He has talked about his journey out of the nursing home to people with disabilities and their families, to politicians and service managers, to staff, and to people in his community.

Connie and John have become Ray's friends and allies. One of the things they help Ray to do is to tell his story; that is their task in writing this chapter with him. The story is Ray's and the chapter will include three of his papers. The lessons about change come

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mostly from John and Connie's reflections on Ray's story which Ray has reviewed and approved.

Ray's lives in one of the United States, but we think its lessons can help anyone who wants to work for change in a system that segregates people with disabilities and takes away their choices about where to live and how to organize the help they need. Where we live, in Georgia, nursing homes are the most common services that separate disabled people from the community and control their lives. In other places, separation and control happen in institutions, or hostels, or group homes, or even in supported living services. The details of the system's rules are different from place to place, but we think that there are many similarities in what it takes to make systems fit better to the lives people want to live. At the end of this paper we will summarize the lessons for systems change we have learned as Ray has moved out on his own.

Why and how does Ray write?

Ray takes time to make up his mind about things. His first answer to a question is usually very short, and is far from including everything that he thinks or feels about a subject. He thinks hard and carefully about what he wants for himself and for other people with disabilities. His ideas come to him a bit at a time. Ray does not read or write, so he likes to have someone he trusts to act as his scribe, writing down his ideas as they come to him and then helping him organize them. When he has an idea, he will often call on the telephone and dictate a note, or ask someone nearby to write down the idea in his notebook. Once he has a number of ideas, he likes to have them typed on a computer and read back to him, because that makes it easy for him to rearrange the order of his thoughts and choose just the words he wants. When a paper suits him, he usually takes multiple copies of the final version and shares them widely. Connie has been Ray's scribe more often than anyone else.

Ray usually writes in order to work for change. He has written testimony for public hearings about services to people with disabilities, letters to politicians, and talks for conferences. Because it can be difficult for people to understand his speech, he usually asks someone else to read his papers for him, and then he answers questions.

Sometimes, Ray wants to write about a question so he can understand something better for himself. He has dictated several notes for himself about difficulties he has in effectively directing his personal assistants, especially his paid roommates.

Two kinds of change

From time to time, people decide to change their living arrangements. They move to a larger or smaller place, or move in with someone, or move out to be on their own. People with disabilities who need everyday assistance provided by a service system often find these moves hard to make. Too often, the service system decides where a person will live, and with whom, and when a person will move, and even what kind of furniture they will have. Usually these decisions are based on professional assessments, though it is hard to see why professional skill entitles control of someone's living arrangements.

Rules make service systems: rules about who makes decisions and how decisions are made; rules about how money can be spent and who can spend it; rules about what kinds of assistance are allowed and how much assistance will be available. These rules are written down in laws and regulations and policies and plans and budgets and protocols and system workers produce documentation that proves that they are following them. Behind the rules there are beliefs about how life can and should be for people with disabilities; some of these beliefs are written down, but most of them are taken for granted. The beliefs behind the rules may be so powerful that people in the system take them as the way things are and have to be. People reckon, "That's just reality."

Change within the rules

Sometimes a person wants a change that the service system can assist within its current rules and beliefs. The person may have to wait for necessary assistance to become available, or to argue a case with officials, or to lobby for more funds for the service system, but people in the system can do what needs to be done by following the rules. Problems have to do with resources: having money enough, or properly qualified staff enough, or space enough to do what's needed.

Sometimes a change that makes sense for a person isn't possible within the system's present rules and beliefs. Often people shorten this sentence and simply say, "That change isn't possible." When they forget that the system works through actions that follow changeable rules and beliefs, they shrink the world of opportunities. When they stop even wondering about possibilities outside the system's rules and beliefs, the world of opportunities shrinks even more because people's ideas about a desirable future shrivel to fit what the system offers.

Changing the rules

There is a chance to make the world of opportunities bigger whenever a group of people takes the courage to ask, "Why isn't this sensible change possible? What would it take to make it happen?" There is only a chance of positive change, not a certainty, because many people hold on to the rules and beliefs that make the system. Even if they don't like the way it works, the system provides them or someone they love with assistance, or it provides them with a job and an income and a career, or some of its buildings or routines or accomplishments give them a feeling of satisfaction and familiarity that they would be fearful or sad to lose. As long as people stay inside the beliefs that make the system, they cannot imagine changing it when it frustrates and angers them by ruling out possibilities that make sense, or even when it dominates their lives.

A crack opens in the system

Seven years ago in Georgia, system rules didn't allow peopled with disabilities to get more than a few hours of paid assistance a day in their own homes, and the kinds of tasks that assistants could do were very tightly defined in medical terms. Most people with severe disabilities either lived with their families or in a nursing home.

Seven years ago, Ray was in his ninth year of living in a nursing home. Because his mother couldn't physically assist him anymore, he knew his family had done all they could, and there was nowhere else for him to go. The nursing home was all there was to "reality" for him and everyone he knew. Ray made the best of it. His family had found a good nursing home near their homes and visited him. He went out to church and on whatever outings the nursing home organized. He kept busy.

Seven years ago a small group of disabled activists and a few of their allies created a small window of opportunity to shift the system's rules. Two disabled organizers had created ways to make their living that allowed them to bring people together to work on breaking the nursing home's monopoly on "reality " for people with severe disabilities. This meant learning how the political system worked: who to lobby, how to pressure, when to try to influence the process of law making, budgeting, and planning. It meant staying coordinated with other activists working to open up jobs, housing, heath care, and public transposition to disabled people. It meant learning the system's rules so well that they know them better than most people who work full time managing the system. So when technical changes in laws and funding rules made more flexibility possible, a small and determined group of people were ready to push the system into a new shape.

The organizers' names are Pat Puckett and Mark Johnson. Without their willingness to challenge other people with disabilities to organize themselves, and their skill at learning how to push from outside the system on the details of the way the system works, Ray would still be making the best of the nursing home.

This small but growing network of activists pushed the question, "If the system will pay for someone to live in a nursing home, why won't it pay for the personal assistance people require to live in their own homes?" They asked this question, and presented their own proposal for system change, over and over and over. And mostly, the people they talked with couldn't hear them, because they were speaking from outside what people took as "reality": most people just knew that people with severe disabilities belong in nursing homes. These change agents got used to having conversations about a system based on new beliefs with people who treated them like visitors from the planet Pluto. And, after two persistent years, a few people inside the system heard enough of the message to create the possibility for the first person in our state to try a new way to live her life her own way. Because she needs assistance with every activity –including assuring that her ventilator continues to breathe for her– her widely publicized ability to live well in her own home disproved the necessity for nursing homes and showed how a change in system rules could make a positive difference. Her name is Jenny Langley, and her personal and political activism opened a tiny crack in Georgia's institutional "reality". Within a year, a pilot program assisted 30 people to live in their own places. This is the crack in the system that grew wide enough to allow Ray the choice to roll free from his nursing home.

Ray gets involved

Part of the strategy for making the first tiny crack in institutional reality bigger was to document what the change meant for people with severe disabilities. Connie helped a group of people with disabilities and family members to study the system and define new beliefs and new rules based on their experience and desires (Lyle O'Brien, 1992). Because the separation of people with disabilities into isolated and competing groups is one of the ways the system maintains control over people's thinking and their lives, the study included some people with physical disabilities and some people with developmental disabilities (the system category that includes most people with intellectual disabilities and cerebral palsy and autism in our state).

This decision brought Ray's friend Fred Pinson into the study. Fred, Ray and Cecil, another man with cerebral palsy, met in the nursing home and supported each other to

deal with the problems of living there. Fred had thought about moving out before, but he and his citizen advocates kept running up against the system rules that made it impossible for him to get the amount and kind of assistance he requires outside of a nursing home. The chance that the system's rules could change revived Fred's interest. He asked Connie and John to join a number of other people in his support circle and they agreed.

One day, Connie, Fred and Cecil were in the nursing home's dining room talking about what it would take for Fred to move into his own home. Ray rolled up and asked what they were talking about. Cecil said, "We're planning a way to escape from here. Do you want to come?" Ray said, "No. But I do need a new TV in my room." Then he asked Connie, "Will you get me a TV?" Connie explained that she was there to help Fred and Cecil figure out how to get out. She did offer to give Ray a ride to check the prices on TV's in several stores.

On the trip to shop for a TV, Ray talked to Connie about getting out of the nursing home. Over the next few weeks, Ray took action to expand his world of possibilities. He asked Fred and Connie lots of questions. He met Jenny Langley and asked her questions about how she organized her personal assistance system. He attended a conference with Fred, Cecil and Connie, where he met Michael Callahan, a leader in developing supported employment for people with multiple disabilities, and learned that, in other states, people with disabilities similar to his were getting the assistance they needed to work in ordinary jobs. He joined in the first meeting of Fred's circle of support and helped Fred make his personal futures plan. He attended a meeting of SAN, the advocacy network organized to change the system and decided to join. He learned that the system was holding public hearings about its plans, and that SAN was encouraging people to testify about the need for change.

After gathering new ideas, Ray thought hard about his own dreams and desires for himself, and he decided he wanted to recruit a circle of support and move out. He asked John to help him make a personal plan for the move.

Ray decided that the decision makers needed to know about his plan, so he testified at the hearing about the medical assistance plan. This is what he said (July-August 1993, Testimony to Georgia Department of Medical Assistance Hearings):

> My name is Ray Browning and I am 35 years old. I have to live in a nursing home and I don't want to. I want out of the nursing home. I want my own place to live and a real job so I can help pay for what I need. I have cerebral palsy, but

I'm not sick. I do need help to get in and out of bed, in and out of a car, with my bath, dressing, buying groceries, cooking, going to the bathroom. I need someone to help me with my money. I want a lift-equipped van and someone to drive it for me. I need a way to get the places I need to go, when I need to go there, like to go to work, to Mt. Zion, my church, and to see my family and friends.

Families need help too. My family took care of me as long as they could. They did not want to put me in a nursing home. Before they did, they looked for help to come to my house, but they couldn't find any. They don't want me in the nursing home, but they can't take care of me without help. My family loves me. They still do lots of things for me now. My mother does my laundry every week, and my brother stops by to fix my wheelchair when it breaks. My father visits me once a week and my uncle cuts my hair. I talk to my mother and my father every day on the telephone. They've done everything they can for me including taking care of me until they couldn't do it anymore. I don't understand why families can't get help at home when they need it.

I don't understand why the government will pay money to keep me in a nursing home and won't pay money to help me get my own place to live with the help I need to live there. I don't understand why the government can't help me get a job so I can pay for some of the things I need.

I don't know how much money the nursing home gets to keep me, but I only get $30.00 a month. In the nursing home I sometimes have to wait for an hour for someone to help me go to the bathroom, and sometimes I have to sit on the toilet for an hour where someone has left me and has not come back for an hour even though I turn the light on. I can't sleep at night because there are two other men in the room who make noise or keep their lights on. There is no place where I can have privacy. There are always people coming in and out or walking around. My things go missing. I see other people wearing my clothes. I don't want a better nursing home. I want my own place and the help I need to live there.

I am learning about some new programs in Georgia. There is one called the Independent Care Waiver* that offers personal assistance services which is what

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* A "waiver" is a way the system suspends some of its rules to allow its workers to do something different. Waivers have their own written rules and monitoring procedures that define exactly how the system will behave when it assists someone under the waiver. The Independent Care Waiver allowed a few people great flexibility in use of system money

I need, but there is not enough money for all the people who need it. I have been told there is no more money for this waiver to support other people until April 1994. There should be more money for things like this to help me live in my own place. There should be money to help families so they don't have to put me in a nursing home.

Ray's family couldn't understand what he was saying about wanting to live in his own place. While their sense of opportunities stayed inside the nursing home, his was expanding rapidly beyond it. His mother worried that people were misleading or even using Ray, because she knew it was unrealistic to think about living outside a nursing home. She was afraid that Ray might anger the nursing home owner and lose his place there. Without the nursing home, she would have no choice but to try and care for him. Ray asked his mother and father to take some time to find out about what was possible. He told them that he wanted and needed their support, but that he would make up his own mind about where to live. Ray's parents have always respected his right to choose, and they agreed to help as much as they could.

Making the long haul

Changing the beliefs and rules that create a system takes a lot of work and can take a long time. For Ray, it took more than two years to get from his first plan to his first lease on an apartment of his own. His motto for these years was, "We'll get there, but we have to take it one day at a time."

Ray didn't wait for the system to change, he worked to change it. SAN (the self advocacy group) and the Disability Rights Center had some money to pay for transportation and personal assistants for members involved in influencing the system and educating themselves. Ray used these funds to attend meetings and conferences. He spoke up about the importance of change every time he had the chance. He lobbied politicians, participated in system planning groups, and talked to his church about getting people out of nursing homes.

Whenever Ray met someone he thought could help him change the system, he asked for their help. This is the paper he gave people to explain his request (February 1995):

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according to an individual plan and budget prepared by the person and their allies but reviewed and approved and closely monitored by the system.

The most important thing I need in order to get out of the nursing home is money from the Independent Care Waiver Program, which is administered by the GA Department of Medical Assistance (DMA).

You can help me get a place in the Independent Care Waiver in three ways:

- Give me rides to and from meetings that will help me get a waiver and take notes for me. Meetings like Self-Advocacy Network (SAN) meetings and DMA and DHR hearings.
- Write letters or call the Governor's office, DMA, and legislators and tell them to put more money into the Independent Care Waiver. Tell them that Ray Browning needs it to get out of the nursing home.
- Give me other ideas or help me meet people you think can help me.

I want people to join my circle of support to help me figure out what to do and how to do it. So far, the whole circle meets every month or two and members work on other things with me in between meetings. When I get my waiver, the circle will get more active in helping me set up my home.

When I get a place in the Independent Care Waiver Program I will need:

- People who I can hire to be my personal assistants. I need very reliable people who will be willing to learn what I need and how I want things done.
- Information on housing in Gwinnett County that is accessible and affordable.

If you want to help me, please write your name, address, and phone number(s) here so I can put it in my book.

Ray has a gift for asking. He is gracious when people help and when they say no or disagree. He is not discouraged when people say no to his requests or even when people don't follow through on what they say they will do.

More than 100 people signed up to help Ray and many of them did. Some people helped in small ways by offering suggestions and encourgement, writing a letter to their state representative, contributing to Ray's van fund, or suggesting another person to contact or another meeting to attend. People gave him rides or helped him arrange rides. Two of the nursing home staff accepted Ray's invitation to provide personal assistance when he went to a meeting or conference, liked working for him, and agreed to work for him when he moved out. Some people offered Ray furnishings for his home. Other

people helped Ray do things he wanted to outside the nursing home, like attending a literacy program at the public library. Some system managers say that Ray's forthright and thoughtful explanations of why he wanted to move out and why he did not want to live in a small group home and his direct request that they do what they could to help him expanded their own beliefs about what their system could and should support.

Ray took responsibility for coordinating action on his own behalf. He has a very good sense of planning and a good memory for what people have committed to do. He can use a touch pad phone if a number is written down and he remembers many telephone numbers. A supply of coins to operate the nursing home pay phone from circle members made it possible for Ray to track and organize their activity and his involvement in the work for system change. Anyone who promised to help out got accustomed to reminder and follow-up calls from Ray.

Ray's political beliefs are generally conservative. He thought very hard about whether or not he would get involved in political demonstrations and civil disobedience organized by disabled activists to raise the issues of creating alternatives to the segregation and professional control of people with disabilities. In the end, he decided that he would participate in direct action to change the system, even if it meant that he would risk getting arrested.

Ray worked hard to make change, and sometimes it seemed like he would never get out of the nursing home. This is Ray's list of things that kept him going (June 1995).

- Having people to listen to me who know that I can think and do not laugh or get scared when I say what my dreams are and what I want.
- Having a circle and a plan so a lot of people can each do a little bit and the little bits fit together.
- Being part of Fred's circle and helping Fred get out.
- Being part of SAN and the Disability Rights Center. Getting involved in politics and testifying at hearings. It helps to keep telling different people what has to change and why it's important. It helps to know you're part of a movement.
- Speaking to groups about people having their own homes and listening for new ideas.
- Finding out about how other people with disabilities live and work and how they set up their personal assistance system.

- Keeping my book of people and ideas.
- Going to conferences, especially about rights, jobs, and homes.
- Fighting to make the nursing home a better place to live while we had to be here (even though it didn't even really work). Getting out of the nursing home as much as possible.*

In August of 1995, a place in the Independent Care funding stream became available unexpectedly and Ray moved at short notice into his own apartment. His personal assistants and his roommate were people he had recruited himself. His housewarming party brought many of the people who had supported him together to celebrate. He also invited several people with disabilities he had met through SAN They had not yet decided whether to seek their way out of nursing homes. Ray wanted them to see what is possible when people work together to move outside the system's usual rules and beliefs.

Some Lessons for Organizers

- The more widely and strongly people hold system shaping beliefs as defining the limits of reality, the more important it is to build a base for change outside the system. A small group must support one another to define and pursue possibilities which challenge the system's beliefs and strengthen the case for new rules.
- The more skill and energy organizers can devote to building the base group, the faster and more widely the movement for change can grow. Full time organizers seldom have much in the way of income or job security; some organizers use their benefits income to fund their social change work and can extend their effectiveness greatly if they can find help with telephone, copying, faxing, mailing, and transport expenses.
- To change the system, some people in the base group need to learn the political processes for changing the system rules by getting directly involved (don't forget work for political parties).
- Some people need to learn the details of system rules and workings very well, while not mistaking them for unchangable reality. The goal is to understand what the rules already allow that's not being done and to identify exactly the rules that must change if things are to be different.

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* The nursing home took a neutral position on Ray's work to make change. They allowed visits and meetings with no hassles for most of the time Ray was working to get out and did not interfere with Ray coming and going as he chose.

- Find a question that challenges the beliefs that shape the system's rules and keep asking it to anyone with power in the system.
- The base group needs to have an answer to its question, but getting people wondering about the question is more important at first than getting them to accept your answer. Once people accept the question, they usually have good ideas about how to improve the answer.
- Don't expect people to even understand the question at first. Remember, it may come from outside their sense of what reality is.
- As soon as possible, use some system resources to create the difference you want to make in the life of at least one person. A system insider who believes in a new possibility can free resources in the name of a pilot project or an experiment or a response to political pressure. Inventing a new way of being takes courage, creative problem solving, negotiating skill, and willingness to work hard. All these skills can be developed by actually making the change.
- Even though the existence of a new way to live disproves the beliefs that shape the system, expect most people to dismiss it as a weird exception instead of changing their beliefs. But, at least a few other people will now be able to see expanded possibilities and join or support the base group.
- Sometimes small amounts of system money can be found to support studies, evaluations, plans, and consultation exercises that explore the base group's change question. Do a good job of meeting the system's needs for information and ideas in a way that puts people with disabilities in charge and brings people with disabilities together to explore their experience in terms of the base group's question. The studies and plans won't change the system, but they can expand the base group, clarify thinking, and support problem solving. Budgets for this kind of work need to allow for the expenses of transportation, communication, and personal assistance required by people with disabilities.
- When you take system money, deliver what you promised, on time and in an attractive form. Most people inside the system won't be persuaded by documents and presentations, but keeping agreements protects credibility.
- Work across a wide spectrum of approaches to change from joining system working groups to civil disobedience. Keep asking how involvement in system activities like planning exercises and providing representation on committees helps move change forward and pull back to minimal involvement when there is not much promise of change.
- Always keep a human face on the issues.

- Always look for what the next new person with a disability can contribute to changing the system.

Reference

Connie Lyle O'Brien (1992). *To Boldly go...* Atlanta, GA: Georgia Governor's Council on Developmental Disabilities.